

Insight Report: Online public involvement session on early life respiratory infections and their impact on lung age

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Background

A group of researchers at Imperial College London (“Imperial”) (some of whom are also part of the National Institute for Health and Care Research (NIHR) Imperial Biomedical Research Centre (BRC)) are applying for £26M over 7 years (initially) from the Medical Research Centre (MRC) for a MRC Centre of Research Excellence.). The funding application will focus on the theme of healthy ageing and lifestyle and more specifically early life respiratory infections and how this impacts how the lungs age, grow, and develop to improve healthy life expectancy. The following three proposed questions intend to be answered by the research:

1. How do respiratory infections in children (0 to 18 years) impact lung ageing and the lung health of their household?
2. Which children need an intervention (something done to address their health) and when?
3. How can we change and improve the lung health of children and their household?

To assist with the development of the MRC grant application, the NIHR Imperial Patient Experience Research Centre (PERC), a core facility of the Imperial BRC, facilitated an online discussion session to gather insights from people who are parents/guardians/carers of children aged between 0-18 years old and who live in England.

The Imperial BRC is a collaboration between Imperial College London and Imperial College Healthcare NHS Trust, which is funded by NIHR until November 2027. The Imperial BRC has 14 areas of research focus (including Respiratory, Infection and Antimicrobial Infection and Social, Genetic and Environmental Determinants of Health which all include a paediatric focus), as well as PERC which supports all the Imperial BRC themes.

Public Involvement is defined by the NIHR as “research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them”¹.

“Public” is defined by NIHR as including patients, potential patients, carers, and people who use health and social care services as well as people from specific communities and from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they are current patients or not.

Approach and purpose

Public involvement was considered an essential part of the development process for the MRC grant application. Imperial researchers aimed to explore the views of parents/carers/guardians of children 0 to 18 years and obtain their feedback on the proposed funding application and its approach.

The aims of this online session were to:

1. Introduce and explain the MRC funding application and the proposed research questions (20 minutes)
2. Give attendees an opportunity to ask questions (15 minutes)

¹ <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#definitions-of-involvement-engagement-and-participation>

3. Facilitate small group discussions in Zoom breakout rooms (discussion questions outlined below), with attendees divided into breakrooms based on the age of their children (50 minutes):
 - i. Are the research questions proposed relevant to your community?
 - ii. What would you think about you/your children/parents being asked to provide the following things for this type of research:
 - a) a blood sample
 - b) and/or nose or throat swabs
 - c) and/or breathing tests
 - d) your health data
 - e) household samples: dust, air, mould, temperature
 - iii. How often could we do the tests e.g. 6 monthly and after a child becomes unwell during study?
 - iv. What would you think about doing the tests yourself at home? Or would you prefer a researcher visit your home to collect this information from your family (including your children)?
 - a) any challenges/barriers?
 - v. What would encourage people/families to take part (e.g. regular access to specialist team if their child becomes unwell, receive a report on household samples)?

Call overview and agenda

The online discussion was hosted on Monday 15th of January 2024 (5:30pm to 7pm) via Zoom and was attended by 15 members of the public from a wide range of backgrounds (see **Appendix 1** for attendee's demographic characteristics).

During the first part of the session, Imperial researchers provided an introduction to the MRC grant application including the proposed research questions and how the researchers propose to answer these questions. This was followed by an opportunity for the attendees to ask questions.

The session included three breakout rooms, with most attendees divided into breakout rooms based on the age of their children, as follows:

1. Breakout room 1: parents/carers/guardians of children aged between 0-4 years old.
2. Breakout room 2: parents/carers/guardians of children aged between 5-12 years old.
3. Breakout room 3: parents/carers/guardians of children aged between 13-18 years old.

Between four and six members of the public were involved in each breakout room discussion. Within each breakout room, there were either one or two researchers and one PERC team member to facilitate the discussion. The discussion in the breakout rooms centred around the proposed discussion questions (outlined above), which had been agreed with the researchers ahead of the session. PERC staff members supported the facilitation of breakout room discussions and assisted with any technical difficulties that arose.

Attendee recruitment

An email invite was sent to Imperial BRC Community Partners across different BRC research themes. In addition, the opportunity to be part of the online session was sent to members of the public through the PERC newsletter with the requirement that the attendees be parents/carers/guardians of children 0 -18 years.

Feedback

Following the session, attendees were sent an anonymous online feedback form to provide their insights on the session, and to provide any additional feedback on the discussion questions posed in the breakout rooms (see **Appendix 2**). The feedback provided in relation to the questions discussed in the breakout rooms was integrated into the Key Insights Summary below.

Payment

In accordance with the NIHR payment guidance, attendees were paid £37.50 for their time as well as a £5 contribution to Wi-Fi/data expenses for accessing a virtual meeting.

Key Insights Summary

Insights provided during the session by attendees regarding the MRC grant application are summarised below.

Relevance of proposed research questions

Public contributors were **generally supportive** of the research questions to be addressed by the proposal. In particular, those who had been **part of research projects** (or whose children had) were supportive of increasing knowledge in the proposed research areas.

Specific areas of interest for the research identified by attendees included:

- the impact that **air pollution** could have on their children's health
- if areas in **low traffic zones** correlated with improvements in children's health
- **Covid-19** as a possible factor that worsened children's respiratory symptoms
- the impact of **acquiring antibiotics over the counter** overseas and bringing them back to the UK, and the impact of antimicrobial resistance
- parents lacking enough **knowledge about infections** generally and to also support their children constantly affected by infections.

Suggested amendments to the research questions (see 'Background' for the research questions) included:

- adding "**and for how long**" to the following research question "Which children need an intervention (something done to address their health) and when?"
- adding "**and for how long**" to the following research question "How can we change and improve the lung health of children and their household?"
- that research question three focus on exploring **dietary aspects and the use of probiotics**
- developing a **multiple-choice questionnaire** for research participants with the aim of consulting them about the factors they would like to be explored in research question number three.

Acceptability of providing certain samples for the research

Blood samples (via a finger prick)

Many attendees considered that parents would be reluctant to take **blood samples** from their children for the following reasons:

- children **dislike blood tests and needles**
- it would be frightening for children who are **neurodiverse**
- it is very upsetting for a **parent to do these tests** on their own child
- concern about **where** the blood samples are going to go
- concern about **who will have access** to the results

One advantage identified of a blood test would be if it identified whether the infection was **viral or bacterial** (as this is a continuing issue and concern).

Attendees provided suggestions to **address the challenges of taking finger prick blood samples** including:

- researchers start to take other proposed samples first, e.g. as household samples to **build trust** with participants
- **simplify information** presented to parents/guardians/carers e.g. in animated videos or using pictures and colours or
- **illustrate** the information through comics for children (e.g., a superhero taking a blood test)
- **make the research more appealing** e.g. emphasizing the difference it would make for parents/guardians/carers if blood tests provided additional relevant health information about their children.

Household samples e.g. dust, air, mould, temperature

Public contributors were generally supportive of collection of household samples dust, air, mould, temperature **and considered this would be more appealing to those**

interested to know the results and take action if required. Attendees highlighted the following potential concerns with the collection of household samples:

- anxiety about being judged due to **poor housing conditions**
- feeling self-conscious about the **cleanliness of their homes**, which could impact the test results if they undertook additional cleaning ahead of a sample collection.

Suggestions to improve the acceptability of collection of household samples included:

- **sharing the test results** with participants
- providing the **option** to either take the samples themselves or have a researcher collect the samples.

Nose or throat swabs

Public contributors had mixed opinions regarding **nose or throat swabs**, some suggested these would be acceptable and some suggested these tests would not be ideal after having used them in the Covid-19 pandemic especially undertaking swabs on children were not supported.

Breathing tests

Attendees who explored the acceptability of this test said they considered this test would be acceptable.

Provision of health data

Attendees from only one breakout room explored the acceptability of providing **health data** as part of this proposed research programme, and they supported the use of health data including that collected by GPs, however, concern was expressed about the **security of patient data**. They also suggested **informing research participants from the outset** of the project about the collection or linkage of their health data and obtaining informed consent.

Frequency of Tests

Attendees had mixed views regarding the **tests' frequency**, with some expressing that conducting tests at 3 months, 6 months, or a year would not affect them. In contrast, others expressed that it would not be appropriate to perform a test more frequently than 6 months. Additionally, it was

suggested that participants be provided with the option to take more samples during winter, when infections are more frequent, or offer additional tests in case of a child having a potential infection.

Views on sample collection

Overall, attendees had **mixed views** on the ways in which samples were to be collected.

Samples collected by household

Attendees suggested that having these results may give families some **control over their situation** in situations where there is damp etc especially if it could be linked to potential home improvements of air quality by local authorities and housing associations. It would be important to know what the **research team's responsibility** would be to let the family know if the results are relevant to the family's health when the research team take measurements in the home.

- Some highlighted that it would be preferable to **take the tests themselves at home** and some expressed that it would be preferable if the samples were collected by a healthcare professional or a researcher.
- However, one attendee would prefer if samples were collected by a **healthcare professional** and not a researcher, although it would depend on how well the researcher was trained.
- It was suggested having a **video** explaining how to take the sample.

Support for parents/guardians/carers taking the samples at home included:

- that the sample could be taken at their **convenience**
- family members (including children) would not be worried about who is **visiting their home**

Possible challenges of participants **taking the tests themselves at home**, included:

- lack of information and **training provided to participants** to take the tests. One attendee highlighted that it could be worrying to take the sample incorrectly, regardless of the information provided
- the risk of **sample contamination**
- the possibility that participants may **postpone the sample collection**.

Samples collected by researchers

Support for researchers collecting samples included:

- **effectiveness of sample collection**, due to the training and information that healthcare professionals bring
- less risk of **sample contamination**
- **teenagers** may find it difficult to visit a specific location to have a test with schoolwork/university commitments and it would be easier to send a kit to the house with instructions that they could then post back, or someone could come to the house to collect

Concerns regarding having a **researcher collect samples from homes** included:

- some cultures/people may **prefer females** to attend the home rather than males
- family members (including children) may be **worried about a person** from outside their family entering their home
- anxiety about being judged and **children being removed** if the home is damp and this being seen as neglect. It would need to be clear that this would not happen.

- women living alone may not feel safe **having a stranger** visit their home
- **safeguarding** issues regarding the children and family
- **continuity**: if a researcher is visiting the home, then having the same person will be important for the family.

Alternative approaches to sample collection

- **Schools** were suggested as a possible place to undertake tests on children.
- A **flexible approach** was also suggested where all participants, due to people's different situations and preferences, should be given the option of taking the test themselves or having a researcher visit their home to collect the samples. Families could be asked for their preferences when enrolling them into the study.
- At the **beginning of the study**, a healthcare professional could collect the samples and, when participants feel comfortable, they could start collecting the samples themselves.

Strategies to encourage research participation

Most attendees were supportive of the research being integrated into the community, enabling the involvement and engagement of both participants and communities, with informed consent being vital. Other strategies suggested were:

- **building trust with communities** to encourage research participation including researchers going into communities and speaking with them
- ensuring different types of family from **diverse backgrounds and those at high risk of respiratory diseases** have confidence to take part in the study: researchers should consider how they can facilitate this including through building relationships with community leaders and undertaking community outreach
- raise awareness through a **campaign** on the importance of getting involved in this research, what the benefits are, and what the outcomes of research will be.
- **utilising schools** to engage with and explain the research to both parents and children. Part of the study could be a **community project** or have some learning associated with it that would appeal to schools.
- emphasize the **science/experimental side** to engage young people. e.g. children like things like YouTube channel MythBusters and TV show Operation Ouch. Could young people take part in an experiment, or contribute data and see their results?
- highlight the **benefits of the study** to improve research participation:
 - families will want to understand the **short-term benefits** of being part of the study and may be motivated by 'fear of missing out' if others will benefit from the study
 - the benefits of the study should **outweigh the burden** of participating in the study
 - the study should be **mutually beneficial** for participants e.g. collecting comprehensive data for the benefit of all family members.
- **positioning** is important so no one is specifically targeted i.e. "we have representation from these communities already, we do not have enough representation from 'this' community".
- **carer forums** were highlighted as a way to collect views on including children and young people with additional needs
- providing **incentives**:
 - for kids and teenagers **financial, education and food** could be motivating however making friends may also be an incentive

- for adults, both **financial incentives and education** are important. Education for parents whose young children are constantly affected by infections where the parents are not clear what they can do or how serious the infections are
- **appropriate communication and provision of information** to children and families with the **information** including the benefits of the study and its outcomes
- ensuring the study is designed so that **feedback is provided** to participants about the outcomes of the study as often as possible and definitely at the end (in appropriate language and mediums) (which it was noted researchers often do not provide).
- for **children and young people**, preparing them, letting them know what's coming and having upfront information is key, so that they're prepared and have got capacity to process and think about it.
- researchers should reach out to **underserved communities** e.g. having a session in a community centre and explain about the research and how they can get involved.
- **community researchers** could help researchers to engage with communities and build trust.

Recommendations on **how to provide information** included:

- providing information in **different languages**
- using **different formats** such as campaigns, videos and comics, and
- using **different channels** of communication such as YouTube and TV shows
- some young people need **additional support** to understand what's being said to them, with additional support provided to their parent/guardian/carer who can help them.

Factors affecting research participation

- Attendees mentioned **the length of the study** as a factor that may influence research participation, both positively (a period of 5 years being a good duration to take part in a study) and negatively, with attendees suggesting to recruit families **initially for a period of one year**, enabling them to understand the benefits and burden of the study, and then asking them to sign up for a longer period.
- It was noted that families in which there is a **pre-existing health issue**, who may already have some understanding that the research could benefit other families, are likely to be motivated to take part and by the possibility of the research **benefiting their local community**
- Some children will be motivated through knowing that there was some **community benefit**, specifically to the local community rather than benefits nationally.

Other potential **challenges of recruiting** to this study include:

- **communication** with children and young adults during the study period as they get older their situation and preferences may change including **their ability to consent** to take part in the study for themselves. For this reason, researchers should consider different ways of engaging with them.
- some might not see this research as directly affecting them currently. People need to understand what they will get out of the study in the short term as they may not see the long-term benefits in terms of "**health outcomes**" in later life and may not be aware of what a "health outcome" is

Appendix 1: Demographic characteristics of attendees

Table 1: Demographic characteristics of attendees (provided voluntarily) (N=15)

Characteristics	n (%)
Attendees age groups (in years)	
17-25	0 (0.0)
26-35	1 (6.6)
36-45	2 (13.3)
46-56	6 (40%)
56-65	1 (6.6)
66 – 75	0 (0.0)
76+	0 (0.0)
Prefer not to say	5 (33.3)
Gender	
Female	12 (80)
Male	3 (20)
Prefer not to say	0 (0.0)
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	2 (13.3)
Irish	0 (0.0)
Gypsy or Irish Traveller	0 (0.0)
Other White background	3 (20)
Mixed/Multiple Ethnicity	
White and Black African	1 (6.6)
White and Black Caribbean	0 (0.0)
White and Asian	0 (0.0)
Other Mixed/Multiple background	0 (0.0)
Asian/Asian British	
Indian	3 (20)
Pakistani	1 (6.6)
Bangladeshi	1 (6.6)
Chinese	0 (0.0)
Other Asian background	0 (0.0)
Black/African/Caribbean/Black British	
African	3 (20)
Caribbean	0 (0.0)
Other Black/African/Caribbean background	0 (0.0)
Other	
Arab	1 (6.6)
Any other ethnic group	0 (0.0)

Prefer not to say	0 (0.0)
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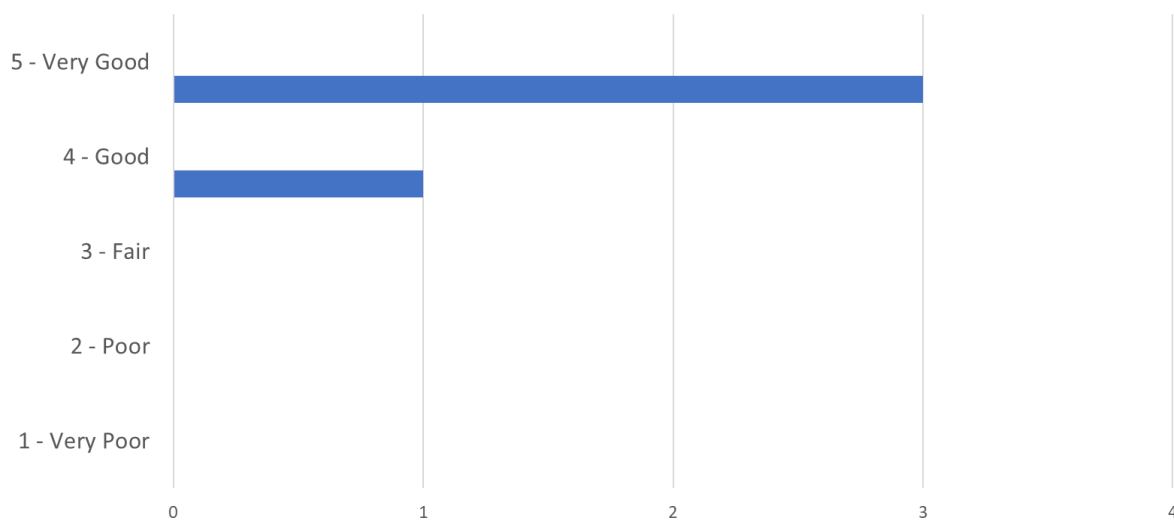
Ages of attendees' children	number of attendees with children aged in this age range²
0-4 years old	2
5-12 years old	6
13-18 years old	9
Information not provided	2

²Please note that attendees were asked to provide the age/ages of their child/children and therefore, some attendees' children are in different age ranges.

Appendix 2: Post-session feedback from attendees (n=4/15)

A post-session anonymous feedback form was sent to attendees who were asked to provide their insights about the session including how they rated it and their motivations for joining. Respondents were also asked whether they had any further responses to the questions posed in the breakout rooms and these responses were consolidated into the Key Insights Summary.

Question 1.1: On a scale of 1-5, how would you rate the session?

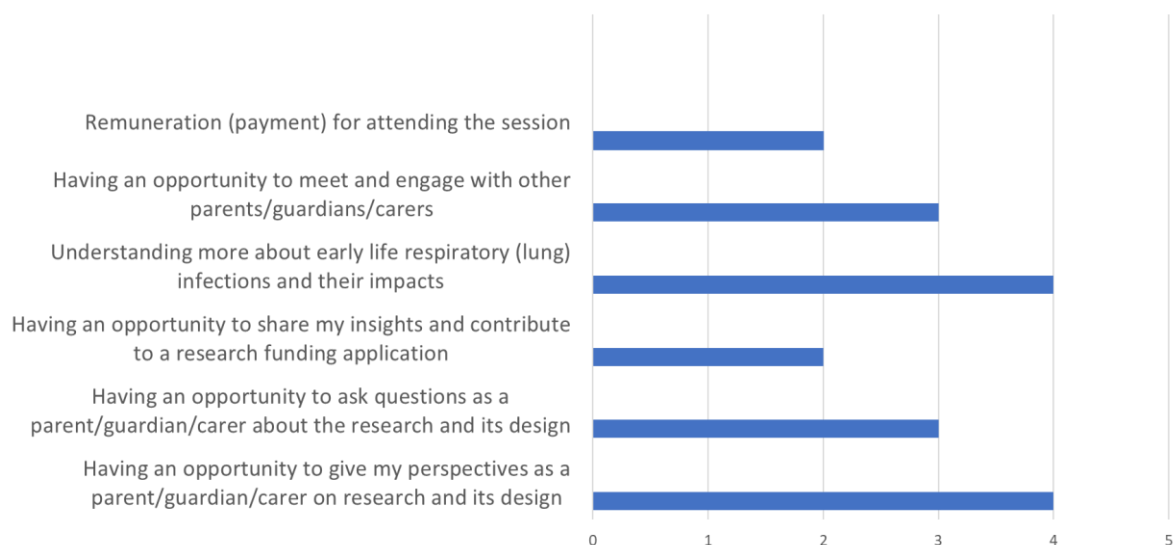


Answer	Count	%
1 - Very Poor	0	0
2 - Poor	0	0
3 - Fair	0	0
4 - Good	1	25
5 - Very Good	3	75

Question 1.2: Please tell us why you chose the above rating:

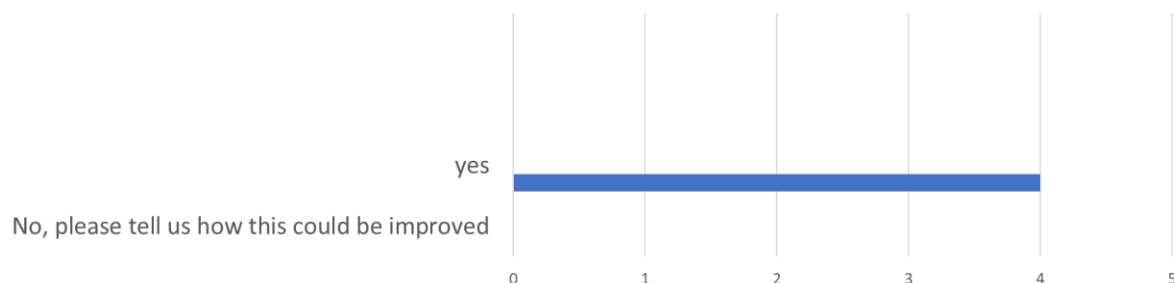
Very informative, explained well.
Well organised. Objectives and questions that you wanted answered were clear.
Very interesting subject and group and the researchers were very informative.
I enjoyed the session.

Question 2: What were your main motivations for attending the session? (Feel free to choose more than one)



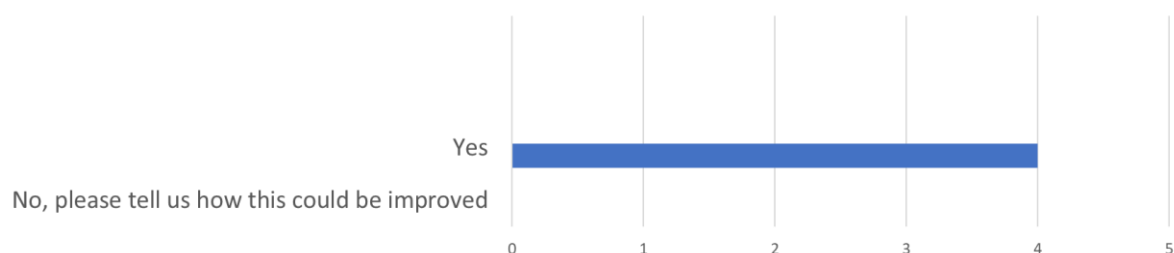
Answer	Count	%
Having an opportunity to give my perspectives as a parent/guardian/carer on research and its design	4	22
Having an opportunity to ask questions as a parent/guardian/carer about the research and its design	3	17
Having an opportunity to share my insights and contribute to a research funding application	2	11
Understanding more about early life respiratory (lung) infections and their impacts	4	22
Having an opportunity to meet and engage with other parents/guardians/carers	3	17
Remuneration (payment) for attending the session	2	11
Other - please specify	0	0

Question 3: Do you think you were provided with sufficient information about the session prior to attending?



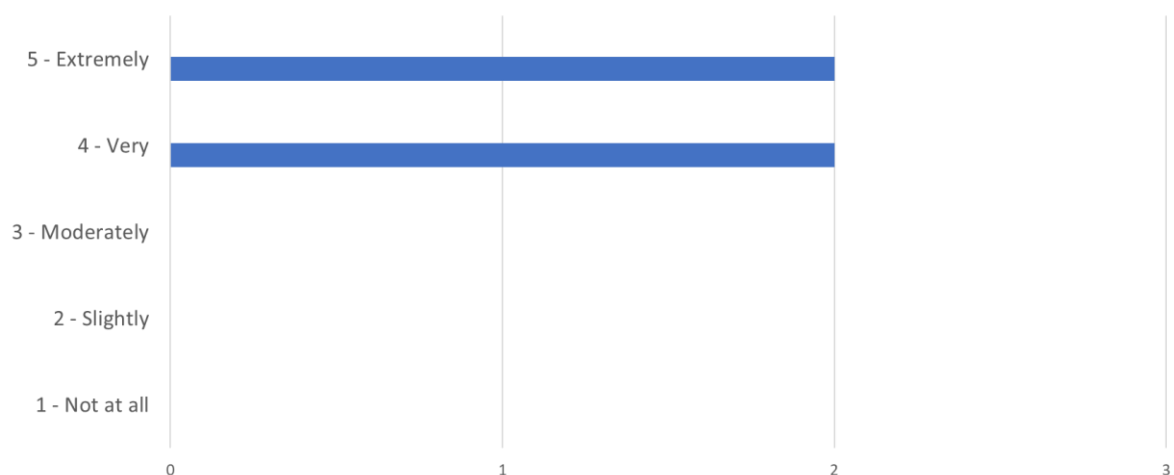
Answer	Count	%
Yes	4	100
No, please tell us how this could be improved	0	0

Question 4: Did you find the presentations easy to understand?



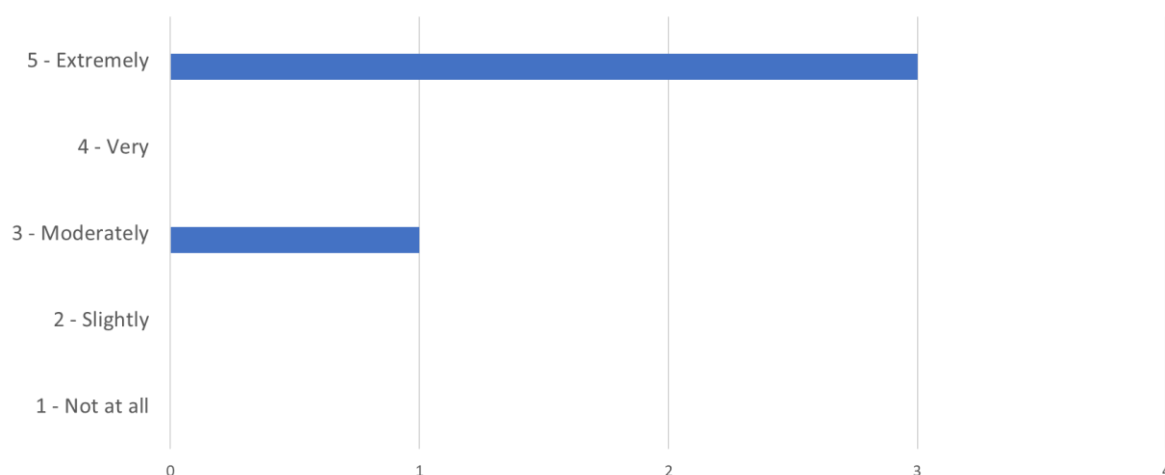
Answer	Count	%
Yes	4	100
No, please tell us how this could be improved	0	0

Question 5: How informative did you find this session?



Answer	Count	%
1 - Not at all	0	0
2 - Slightly	0	0
3 - Moderately	0	0
4 - Very	2	50
5 - Extremely	2	50

Question 6: How likely are you to attend a session like this again?



Answer	Count	%
1 - Not at all	0	0
2 - Slightly	0	0
3 - Moderately	1	25
4 - Very	0	0
5 - Extremely	3	75